

# Information

## Organ Transplants

### A Search for Health Policy at the State Level

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UNTIL THE FALL OF 1987, Oregonians' interest in the issue of public financing of organ transplants ranked well below their concern for the infestation of the Gypsy moth in our forests. As it became obvious, however, that actual lives were being prematurely lost as a result of a lack of state funding for specific medical procedures, public interest rose precipitously. Wide awareness of the issue began as the media vibrated to the fate of 7-year-old Adam Jacoby ("Coby") Howard, a leukemia patient who needed a bone marrow transplant to survive. He was the child of a single parent on Medicaid and ineligible for government funding. Telephones to legislators buzzed and the public outcry grew while some charitable souls passed the hat in the hope of raising \$70,000 in time to save the lad. He died last winter, but the issue lives on to haunt Oregonians and their legislative representatives, as it will, in all probability, eventually haunt the nation and Congress. How to pay for expensive high-technology medical services to the poor presents a grave and undeniable contradiction to our tradition of all for everyone. Like it or not, Oregon has become the first state in the union to meet the problem of health rationing head on with a deliberate policy decision.

The Oregon legislature has a particularly swift and open accountability to the public for how it spends public money because the tax base is limited. Without a sales tax, present state income is desultory as the nation slowly recovers from the national recession of 1981 to 1985. The state constitution forbids bonded indebtedness for public services. The recalcitrant issue of organ transplants passed over the 1987 legislature in a health budget that provided few increases in services for the medically indigent while eliminating the provision to finance organ transplants—with the exception of corneal and kidney transplants. These were left in the bill because corneal transplants represent a relatively infinitesimal amount of money and kidney transplants are reimbursed under a federal program. Neither offered any strain to a slim state budget. In the final days of the 1987 session, with the legislators largely unaware of the implicit life-and-death issue and without open legislative exploration and debate, financing of heart, liver, lung, and bone marrow transplants was eliminated, effective July 17, 1987.

When Coby Howard's family discovered his plight of needing \$70,000 before the regional hospital would do a

bone marrow transplant, they appealed to state authorities for dispensation of the recent legal restrictions. What followed is characterized by the family as a "frightful runaround." Differing and conflicting decisions were handed down by various levels of the administration, finally ending as a blanket refusal to fund the indicated treatment.

The family next appealed to the Oregon State Emergency Board, made up of legislators empowered to alter the budget during the legislature's interim. This body started the biennium with \$25 million, but by the time the issue of funding organ transplants was brought before them, they had already spent \$17 million meeting an unplanned expense of a plague of forest fires. Understandably, they were most anxious to make the best possible use of the remaining funds and, in considering the plea for organ transplants, they also had to consider a plea from another medically neglected portion of the population—poor pregnant mothers and their children. Prenatal services in Oregon for the poor had completely evaporated so that the only medical help a poor pregnant Oregonian could expect was admission to hospital to deliver *after* she proved she was in labor. Consequently, the issue before the Emergency Board became framed as "all or nothing"—whether the limited state funds would be used for a few persons needing organ transplants or for many others, including approximately 2,200 poor pregnant women. The decision was anything but a decision by default, for the Emergency Board carefully considered and heatedly debated what to do, finally going for "other" services by one vote.

Coby Howard's family then went public in an attempt to raise medical funds directly. Torn with mixed feelings, they turned the dying child into a publicity event and his smiling, wan face became familiar on local television screens. They raised but \$30,000 of the necessary \$70,000 before he died without benefit of an accepted medical treatment.

In another part of the state, centering on the city of Bend, which boasts of a much stronger sense of community than the metropolitan Portland area Coby had called home, a similar drama unfolded. There, a 17-year-old boy with a similar disease also became a publicity event, but here the prerequisite \$70,000 was raised by numerous, intense charity events. This lad is now alive. Success in the Bend area quickly turned to chagrin with the state's epidemiologist's prediction that 34 medically poor persons could be expected to need organ transplants before the legislature met again in 1989.

Continuing reaction to the issue has varied. Like most news, the transplant issue had a two-month life span before television and newspaper coverage turned to police scandals, local teenaged gang warfare, and more global violence. The issue has never been lost to the public or the legislature, however. The inhumanity of an "all or none" policy decision on organ transplants, for recipients and decision makers alike, was clear to the Emergency Board. One of the most reasonable arguments put forth by those seeking transplant funding was the arbitrary and unreasonable deletion of funds for a particular treatment—organ transplants—when other "questionable" treatments such as coronary bypass operations consume considerably more state funds. The Emergency Board, anticipating that the issue will reappear in the 1989 legislative session, recommended that the Interim Committee on Human Services begin a search for a reason-

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able resolution of the issue. In turn, that committee appointed a subcommittee to study the issue for long-term solutions.

One stopgap measure provided by the Emergency Board was the creation of a state trust fund that could accept donations from the public for funding organ transplants for the medically indigent. The fund was intended to secure 62% Medicaid matching funds for any donation. Unfortunately, the fund did not find much support and never met the criterion for implementation of at least \$70,000. Subsequently, the federal Health Care Financing Administration has ruled that anything short of "similar treatment of similarly situated individuals as required by . . . the Consolidated Omnibus Budget Reconciliations Act of 1985" would not be matched with federal funds. The Emergency Board's trust fund has since been eliminated. The charitable approach appears bankrupt.

Other reactions to the implicit moral crisis of allowing citizens to die without benefit of full medical support have followed. In response to the uproar in the Bend area, the local state representative asked Oregon Health Decisions to hold an open forum on the problem of health priorities for the state. Oregon Health Decisions is a citizen network dedicated to promoting education and action on the ethical issues in health care in the belief that the health care system should reflect the values of an informed community. The aim of this and subsequent forums across the state was to develop an informed citizenry, all pointed towards a People's Health Care Parliament, for considered citizen influence on the 1989 state legislature on health priorities for the 1990s.

The first open forum was held on a February 1988 weekend in Bend, and, along with the specific issue of funding organ transplants, the broader implications of health care financing were addressed at three different levels. Those present were assigned to small groups charged with developing a consensus on these issues:

- What portion of the general budget should be assigned to health care?
- What portion of the health budget should be assigned to specific populations (infants, children, adults, and the elderly) and what portion should be assigned to specific health care approaches (acute care, long-term care, chronic care, and prevention)?
- What is the specific preference regarding state funding of organ transplants?

The consensus of each group was reported to all present and then, following an open debate, a consensus for the town-hall meeting arrived at. These findings were brought to the People's Health Care Parliament in September, where the process of small group discussions followed by open consideration and full debate by the 50 representatives from across the state established 15 principles of citizens' values in determining the priorities for health care in Oregon (Table 1). These principles have the attention of legislators and public administrators, so much so that the Oregon Department of Human Services postponed developing its 1989 budget until it received a report from the Parliament.

As for the organ transplant issue, early soundings across the state indicate a low priority in the public's mind. Preliminary findings are that 15% are for state-funded organ transplants, 45% are against, and 40% remain undecided. The predominant wish seems to be for a definitive shift away from funding curative medicine to funding preventive services, a

move reflected in the Emergency Board's decision to fund other services, including prenatal care for indigent mothers and their children. The strongest public expression seems to be for defining and guaranteeing a basic health package for all citizens. Definitive findings await the effect of the Parliament on the next legislative session, however.

The serious problem of allocating of state health funds has also been addressed by other state policy bodies. The Oregon Health Council established basic standards from which some procedures were excluded. Intense debate over each exclusion ended with all excluded procedures being retained, however. The Governor's Task Force on Health Care to the Medically Needy also addressed the problem of health care allocation and surfaced with a number of recommendations, including a proposed 1% tax on all providers to be used in underwriting the cost of care for the 20% of the

TABLE 1.—*Principles for Securing Quality of Life in Allocating Health Care Services\**

*Purpose of Health Services*

The responsibility of government in providing health care resources is to improve the overall quality of life of people by acting within the limits of available financial and other resources.

Overall quality of life is the result of many factors, health being only one of these. Others include economic, political, cultural, environmental, aesthetic, and spiritual aspects of life.

Health-related quality of life includes physical, mental, social, cognitive, and self-care functions, as well as a perception of pain and a sense of well-being.

Allocations for health care have a claim on government resources only to the extent that no alternative use of these resources would produce a greater increase in overall quality of life of the people.

Health care activities should be undertaken to increase the length of life or the health-related quality of life during one's life span, or both.

Quality of life should be one of the ethical standards when allocating health care resources involving insurance and government funds.

*Why Priorities Need to Be Set*

Every person is entitled to adequate health care.

It is necessary to set priorities in health care so long as health care demands and needs exceed society's capacity, or willingness, to pay for them. Thus an "adequate" level of care may be something less than an "optimal" level of care.

*How to Set Priorities*

Setting priorities and allocating resources to health care should be done explicitly and openly, taking careful account of the values of the broad spectrum of the Oregon population. Value judgments should be obtained in such a way that the need and concerns of minority populations are not undervalued.

Both efficiency and equity should be considered in allocating health care services. Efficiency means the greatest amount of appropriate and effective health care benefits for the greatest number of persons is provided with a given amount of money. Equity means that all persons have an equal opportunity to receive available health services.

Allocation of health care resources should be based, in part, on a scale of public attitudes that quantifies the trade-off between length of life and quality of life.

In general a high priority health care activity is one where the personal and social health benefits-to-cost ratio is high.

*Who Sets What Priorities*

The values of the general public should guide planning decisions that affect the allocation of health services resources. As a rule, choices among alternative treatments should be made by the patient, in consultation with the health care provider.

Planning or policy decisions in health care should rest on value judgments made by the general public and those who represent the public and on factual judgment made by appropriate experts.

Private decision makers, including third party payers and health care providers, have a responsibility to oversee the allocation of health care resources to assure that their use is consistent with the values of the general public.

\*From the September 1988 meeting of the Oregon People's Health Care Parliament.

population without access to health care. This recommendation remains improbable because it not only lacks the governor's strong support, but such a tax focuses on the medical providers. The effect would be little more than another form of cost shifting, failing to place the burden of care on a broad citizen base while begging the moral question of who shall and who shall not receive limited health care resources. Yet another group is reviving an old proposal to form a State Health Plan, a statewide preferred provider organization that would pool the state's employee health fund with the funds for care of the indigent as a base that would insure full health care for all enrollees. The actuarial shortfall of this plan runs approximately \$500 million, no small sum in Oregon, and is unlikely to be recovered by economies of scale resulting from making an inefficient health delivery system efficient.

Action is necessary at a number of different levels, and the first is to recognize, as the death of Coby Howard indelibly records, that the supply of health care resources is limited. Neither the public nor the individual practitioner wishes to learn how much sacrifice lies ahead in accepting that the infinite demand for health care has at last reached the limit of willing supply. It is a difficult area for public discourse. It took little time for some ambitious legislators to appear on Oregon television decrying the Emergency Board's decision, "... when we are subsidizing 4-H projects at the state fair to the tune of millions yet allowing children to die for the lack of proper care." Of course, as with all demagoguery, this has a kernel of truth but misses, perhaps purposely, the public's need to know what the limits are. The discourse panders to the public with demagoguery that thoughtful legislators and concerned providers are little more than greedy, thoughtless, and inhumane manipulators of a decrepit system.

Nor on another level can the federal government be expected to fund transplants, the artificial heart, and an assortment of other high-technology procedures as it funded kidney transplants in the 1970s. Congress is just as vulnerable as state legislatures when making hard decisions and needs assurances that the public understands that what is called for are wise decisions in the face of an infinite need for health care services. The lawmakers of the land, at all levels, should be encouraged to consider a systems approach to the problems resulting from the fortunate miracles of medical research. Legislators need to address the process of evaluation with a new profundity.

The policy challenge of equitable introduction and delivery of medical innovations calls for a new and higher level of education of the public and its legislators to alternatives that exist within our health care system. The commercialization of health care delivery has done nothing to solve the underlying policy decision of the public's responsibility for the care of the medically indigent. The effect of corporate thinking on medical delivery has made the system more efficient, partially at the expense of those who no longer can enter it. Business cannot be expected to offer solutions to a

national moral problem evolving from our inequitable health care delivery system. More is not the answer as the question becomes, more for whom? The goal of business and industry is not to produce morals but profits, which are only moral or immoral in the context of a larger public good.

Nor is it enough to have an "expert" delineate an innovative plan for treating the acquired immunodeficiency syndrome or operating on occluded arteries. Worthy as these plans may be, the public, in the form of government, has become responsible for paying for them with tax funds from a limited budget. The role of the expert is clear and necessary in describing what is possible, but the expert cannot and should not be expected to present the limiting, broad policy values that inform a just democracy. Only legislatures, supported by a courageous constituency, can establish the moral yardstick that must decide which "life and death" health benefits should be pursued under existing circumstances.

Working at the local and state level, Oregon Health Decisions is but one effort in educating the public to their considered expression of human values in the life-and-death decisions of modern medicine. Yet their effort has resonated across the nation. In other states similar citizen responses to the public's responsibility have been initiated, and in October the first meeting of a national organization, American Health Decisions, was held in Denver. The debate needs to be carried from the local level, from the bedside, and across the states to the halls of Congress so that we can establish a new moral tradition, a 21st-century approach, to our responsibility for all the needs of the sick and disabled.

One historic life-and-death national policy should be kept in mind as the debate about health care rationing develops—Selective Service. The American public has a proved ability of fairly deciding who will live and who will die. After failing miserably in 1863 with what ended up as the draft riots, we have accomplished those decisions during four wars. Selective Service worked practically and morally for four elementary reasons. First, the public was convinced that decisions had to be made; volunteering would no longer supply enough personnel to the armed forces to save our country. Second, the rules applied for all. Third, the results were public and open to appeal. Fourth, and especially pertinent to medical rationing, specific decisions were made locally by responsible and accountable citizens who could properly evaluate a particular case against local circumstances.

Remembering that we are strong people, we need leadership with the vision to show us clearly what our hard choices are. Only as the values that inform the necessary individual and community sacrifice are articulated by the public can we expect a humane health care system.

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